GOVERNMENT OF INDIA
HEALTH AND FAMILY WELFARE
LOK SABHA

UNSTARRED QUESTION NO:7788
ANSWERED ON:16.05.2000
HAEMOPHILIA PATIENTS
UMMAREDDY VENKATESWARLU

Will the Minister of HEALTH AND FAMILY WELFARE be pleased to state:

(a) the number of haemophilia patients in the country at present;

(b) the number of patients who have received treatment in AIIMS for this disease during the last three years;

(c) the names of hospitals/medical institutions having the facility of the treatment of haemophilia, State-wise;

(d) the details of AHF injection imported during each of the last three years and till date, indicating the cost involved therein;

(e) whether there is a proposal to encourage production of AHF in the country in view of the fact that the patients are unable to afford the high cost of these injections;

(f) whether the Government provide financial assistance to patients for this disease;
(g) if so, the assistance provided during each of the last three years, and the current year, State-wise; and
(h) the steps taken proposed to be taken by the Government to identify the haemophilia patients in the country especially in the rural areas?

Answer

THE MINISTER OF CHEMICAL AND FERTILIZERS

SHRI SURESH P. PRABHU

(a) There is no centralised statewise registry for this disorder. However according to I.C.M.R., an estimated prevalence from hospital based data is 6/100,000 of population with a total of above 65,000 haemophiliacs in the country.

(b) Nearly 200 patients each year during the last three years have received treatment at AIIMS.

(c) Most major metropolitan cities in India have facilities to treat haemophilia. Delhi, Chandigarh, Lucknow, Mumbai, Pune, Madras, Trivandrum, Calcutta possess grater expertise. Besides, few centres are providing cryoprecipitates such as AIIMS, New Delhi; CMC, Vellore; KEM Hospital, Mumbai etc.

(d) The AHF injections are mainly imported by Haemophilia Federation (India) a voluntary self help group organisation.The details of AHF injections imported during each of the last three years, and till date is given below:-

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1997-98  4 million Units worth Rs.1.71 crores
1998-99  6 million  Units worth Rs.2.55 crore
1999-00   3 million Units worth Rs.1.14 crores (shortfall was due to world
  wide shortage)
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(e) There is a Plasma Fractionation Centre at KEM Hospital, Mumbai which processes about 10000 lts. of plasma per year, though it has not year produced AHF. It is producing Factor IX needed for Haemophilia B in addition to other imported blood component like human albumin.

(f) to (h) Financial assistance upto a maximum of Rs.20,000/- (Rupees twenty thousand only) is provided to poor and needy patients who apply for financial assistance out of Health Minister`s Discretionary Grant to partly defray the expenditure of specialised treatment/costly surgical operations for undergoing treatment/operation in any hospital anywhere in India. The Central Government has also set up a National Illness Assistance Fund and formulated guidelines to provide financial assistance for medical treatment of patients, living below poverty line and suffering from major life threatening diseases. All States/UTs have similarly been advised to set up Illness Assistance Funds. It has also been decided that grant-in-aid from Central Government would be released to each of these States/UTs where funds are set up on the lines advised to them.